Challenges and support needs of parents and children when a parent is at end of life: A systematic review

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Abstract

Background: Preparing children for the death of a parent is challenging. Parents are often uncertain if and how to communicate and support their children. Many parents feel it is protecting their children by not telling them about the prognosis. Children less prepared for parental death from a terminal illness are more susceptive to later adversities. To facilitate coping and moderate for such adversities, there is a need to gain insight and understand the experience and challenges confronted by families.

Aim: This review synthesised evidence on the experiences of parents and children when a parent is at end of life to discern their challenges, support needs and factors that facilitated good practice.

Design: Mixed methods systematic review.

Data sources: Four electronic databases (CINAHL, PubMed, PsychINFO and Ovid MEDLINE) using MeSH terms and word searches in October, 2018. Studies were not limited by year of publication, language or country. Grey literature searches were also completed on Google Scholar and OpenGrey.

Results: 7829 records were identified. 27 qualitative and 0 quantitative studies met the inclusion criteria. Eight descriptive themes were identified, further categorised into two broad themes: (1) barriers and facilitators in sharing the news that a parent is dying and (2) strategies to manage the changing situation.

Conclusion: Lack of understanding in relation to the parent's prognosis, denial and feeling ill-equipped were suggested as barriers for parents to share the news with their children. Engagement with social networks, including extended family relatives and peers and maintaining routines such as attending school were suggested supportive by parents and children. Findings are limited primarily to white, middle-class two parent families. A number of areas for future research are identified.

Keywords: *family, children, parents, cancer, advanced cancer, end of life*

What is already known about the topic?

- Preparing for end of life of a parent is a stressful period for the whole family. It appears that parents feel not preparing their children for the death of a parent is protecting them.

- Children prepared for the death of a parent have shown better adjustment and require less input in adulthood with psychiatry, compared to children not prepared for the death of a parent.

What this paper adds?

- Parents perceived lack of emotional strength, unclear understanding of prognosis, children's cognitive developmental stages, as well as tensions between parents, denial and feeling ill-equipped were identified barriers in their provision of sharing the news with their children that their parent was at end of life and dying.

- Although challenging to achieve, maintaining normality and routine, maximising social networks, quality contact and open communication with the end of life and dying parent were identified as supportive coping mechanisms for parents and children when a parent is at end of life.

Implications for practice, theory or policy?

- Findings suggest healthcare professionals need to provide parents with clearer indications where and when possible of a declining situation when prognosis is poor and death is imminent, so they can prepare their children for the impending death of their parent.

- Additional research to identify the challenges and support needs of parents and children of more heterogenous samples of families is needed. In particular, those families who do not avail of support groups and services.

1. Introduction:

There are few experiences more difficult and emotionally devastating for parents than dying whilst they still have dependent children. While talking about death and dying still remains a taboo in Western society, in 2015, it was estimated that 23,600 parents died in the United Kingdom, leaving an estimated 41,000 child dependents [1]. The authors of this review operationalise 'end of life' as when a patient is not on a curative pathway for their illness and are likely to die within the next year. This includes patients whose death is imminent (expected within hours, days or weeks) and those with advanced, progressive, terminal and incurable conditions [2]. End of life for a parent of dependent children is highly stressful [3]. It is also very challenging for the children and research has reported that they are at greater risk of adverse psychological reactions, including increased levels of aggression, despair and social isolation, anxiety, depression and post-traumatic stress disorder, than the general population [4, 5]. However, when parental death is expected, parental support is an important protective factor in preventing such psychosocial adversities in children [6].

While many parents are often uncertain if, and how to communicate with their children when a parent is dying, evidence highlights that children wish to be informed about their parent's illness and prognosis [7]. As a result of being informed, studies demonstrate that children feel less guilty and feel valued, with reduced isolation [8]. A recent study highlighted that when children have an understanding of the dying process and are prepared for the loss, they show quicker adjustment, than those children, who are not informed [9]. Conversely, longitudinal and follow-up bereavement research studies have correlated and reported children unsupported when a parent is at end of life are more susceptive to adversities in their bereavement and later life, including a decline in education, with increased levels of substance abuse, mental health issues and criminality [10, 11]. The benefits of open communication between parents and children

at end of life are clear, in that it maintains and sustains the parent-child relationship and mediates for such adversities [12, 13].

Despite the overriding need and benefit of open communication, many parents appear not to prepare their children for the death of an ill parent, as they feel not preparing is a method of protecting their children from emotional distress. Additionally, parents feel they do not have the language, knowledge, confidence, or emotional strength to do so [14, 15, 16, 17]. They fear their children will not cope with the information and it will cause them harm, while also being concerned about how they will handle their difficult questions. Other aspects which can add to the complexities encountered while parenting at end of life, with dependent children, include differing developmental stage of the children (especially families with adolescents) [18], efforts expended by families to create memories [19], need to mobilise support to meet the practical, emotional and financial needs of the children [20] and fractured and broken families through divorce and separation [21].

Most parents desire knowledge and guidance, as well as emotional, practical and social support, so they can positively and assuredly protect and prepare their children for the death of their parent [20, 22]. This systematic review aims to synthesise the evidence on the experiences of parents and children when a parent of dependent children is at end of life. Specifically, this review will identify from the experience of parents and children their (1) challenges; (2) support needs; and (3) factors that facilitated good practice when a parent of dependent children is at end of life. As a result, the provision of this knowledge will contribute towards the development of supportive interventions, to promote adjustment for future families, as they prepare children for the death of a parent.

2. Methods

This systematic review followed an *a priori* protocol according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols (PRISMA-P) 2015 guidelines, [23] which is a widely

recognised standardised guide which facilitated the development and reporting of this systematic review. The review protocol was registered on PROSPERO before the search was completed (registration no. CRD42018087554).

2.1 Search strategy

Existing literature was systematically searched to identify articles relating to the experiences of parents and children, when a parent with dependent children (<18 years old) is at end of life. Four electronic databases (CINAHL, PubMed, PsycINFO and Ovid MEDLINE) were searched on October, week three, 2018, using both Medical Subject Heading (MeSH) terms and text word searches, to increase the search sensitivity. Boolean operator 'OR' and 'AND' were used to combine search terms to broaden or limit the search results, as appropriate. The search terms (Table 1) were generated in consultation with two experienced subject librarians and the first author [JH]. The fully devised search strategy was peer-reviewed using the PRESS tool [24] by two co-authors [EMcC, CS] (Appendix A). The search strategy was deployed by the first author [JH].

Grey literature searches were conducted using Google Scholar and OpenGrey to identify research not indexed in the electronic databases. All authors of relevant papers were contacted via email for any of their updated or unpublished work.

2.2 Study inclusion and exclusion

A list of inclusion and exclusion criteria (Table 2) was applied to ensure that only studies relevant to address the review aim were included. This included qualitative and qualitative studies using any research design and analysis that investigated adults (specifically parents) at end of life and have dependent children (less than 18 years old). Additionally, studies were only eligible for inclusion if they reported experiences

of parents or children when a parent is at end of life. Studies where death was not expected within a 12-month period, known to the participant or reported were excluded. No restrictions were applied to the location of research, language or year of publication to have a comprehensive understanding of the existing literature.

2.3 Screening

The searches identified 7829 publications of which 2403 duplicates were removed. The remaining 5426 publications were reviewed by title and abstract, by the first author [JH]. 5314 records were excluded during this process. Full-text papers were retrieved for the remaining 112 articles deemed eligible on the basis of title and abstract. The first author [JH] identified 27 qualitative articles relevant, when the full text was assessed. These were confirmed by two co-authors [EMcC, CS]. A PRISMA-P diagram illustrates these findings and explanations for excluded articles at the full-text stage (Figure 1).

2.4 Data extraction and assessment of included studies

The first author [JH] independently extracted data using an extraction sheet in Microsoft Excel (2016). Data was extracted on the author(s), year, country, study aim, research design, sample characteristics, key findings and methodological criticisms. The twenty-seven papers were further reviewed by two co-researchers (EMcC, CS). Any differences in opinion regarding extraction were resolved via discussion. The first author [JH] applied the CASP quality assessment tool [25] for the twenty-seven qualitative studies, which was verified by two co-authors [EMcC, CS] (Appendix B). The CERQual approach was applied to assess the methodological limitations, coherence, relevance and adequacy of the review findings [26]. Subthemes received either a low or moderate confidence rating. Full details can be found in A*ppendix C.*

2.5 Data synthesis

As the twenty-seven eligible studies were qualitative, a thematic synthesis was conducted based on the approach by Thomas and Harden (2008) [27]. This involved three steps: (1) coding of text, (2) developing descriptive themes and (3) generating analytical themes. The first author [JH] coded the findings from the extraction form, line-by-line using NVivo v.11. Through discussion, all authors collectively grouped together similar codes and agreed on descriptive themes that merged together. Together, the authors identified two analytical themes.

3. Results

3.1 Overview

The twenty-seven qualitative studies were published between 2000 and 2018 [5, 8, 9, 13, 18, 19, 20, 21, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46]. Eighteen of the included studies were conducted before the ill parent died and participants included the ill parent, the healthy parent and/or the children. Nine studies were conducted in the bereavement period and included either the bereaved parent and/or the children. All studies reported parental deaths from cancer. The majority of families were recruited via support groups or services, to which many studies suggested the families included were functioning well as a result of attending. Consequently, findings are limited and represent the subset of the population who attend these groups and services. Furthermore, the majority of participants were from two-parent families, well-educated, white and middle-class living in Western populations. Despite not the norm in clinical practice, many families had frequent access to key support workers and coordinators. As a result, it is unclear how the presented findings are transparent to this population as a whole. Full characteristics

of the included studies are presented in Table 3. Eight descriptive themes emerged from the included studies, further categorised into two broad themes: (1) barriers and facilitators in sharing the news that a parent is dying and (2) strategies to manage the changing situation.

3.2 Barriers and facilitators in sharing the news that a parent is dying

All of the studies in this review suggest parents have a keen desire to protect their children from any further distress when their parent is dying from cancer. Protecting their children was described by parents as choosing whether or not to prepare their children for the death of a parent. Identified barriers and facilitators in preparing children for the death of a parent are discussed under the following subthemes: (1) necessity for information about their illness; (2) guidance and help desired and required to share the news; (3) emotions affecting open communication; and (4) parental conflict and informing the children.

3.2.1 Necessity for information about their illness

Of the 27 studies included, a prominent theme across 16 studies was the need to receive information across the illness trajectory. Consequently, where parents did not have clear information or understanding regarding their illness, they reported being ill-equipped to discuss with and prepare their children for the death of their parent. For these parents, they did not feel confident to explain the complexities of their illness and found their children's associated questions particularly difficult [20, 21, 30, 33, 34, 35, 37, 40, 41, 45, 46]. Some bereaved parents felt health professionals avoided providing honest and clear communication to preserve hope and positivity [40]. To prepare their children, ill and healthy parents reported their need to receive detailed and consistent information from health professionals in relation to the prognosis, treatments they would receive, how the disease would progress and health decline, and what death would look like, with associated signs to provide a comprehensive understanding of their illness and impending death [5, 19, 20, 21, 28, 33, 35, 36, 37, 40, 41, 42, 45].

3.2.2 Guidance and help desired and required to share the news

Many parents had a desire for guidance and support with the words and language as how to best communicate with their children, surrounding the impending death of the parent. More specifically, how to prepare them for the physical effect of cancer and the side effects of treatment associated with the parent's actual death [18, 21, 28, 33, 34, 35, 37, 39, 41, 42, 46]. It was highlighted by parents that this guidance needed to be tailored to the developmental [20, 21, 28, 34, 35, 36, 37] and cognitive [34, 35] understanding of their children.

Parents suggested it supportive when they had an understanding as to how their children may respond and react emotionally and behaviourally to losing a parent to cancer [21, 28, 29, 30, 34, 36]. Although only reported in one study, some parents suggested it helpful when they engaged in role-play exercises; an opportunity which provided feedback on how to respond to particular questions, that may be posed by children [21]. Also, being provided with leaflets, websites and children's literature aided both parents' and childrens' understanding [20, 30, 35]. Obtaining guidance and support promoted parents self-reassurance that they were providing their children with age-appropriate information [21, 28, 36, 38].

It was suggested that some families may not have the capacity to openly prepare their children for the death of their parent [28, 36, 38] or may require professional input in fractured families [21]. As a result, some parents had a desire, while a minority expressed a need for a health professional to be present when these difficult conversations with their children were taking place [21, 28, 35]. Despite this, these studies did not explore how a health professional facilitated these complexities.

3.2.3 Emotions affecting open communication

Parents reported avoiding conversations regarding the parent's illness as their method of protecting their children, from the emotional impact, of the inevitable death of that parent [18, 35, 42, 45]. As a consequence of parents' denial of the terminal nature of the cancer, parents suggested they 'just can't go there' [45]. Often, these parents where in denial that death was the reality and were maintaining hope and optimism that treatment may prolong life [18, 20, 37, 38, 39, 41]. As a result, they did not feel the need to directly prepare their children for an uncertain future [20] and often misjudged what their children could comprehend and understand, regarding the severity of the situation [8, 19].

Where open communication was lacking in families, children felt they had a lack of opportunity to admit how they were feeling. Often reluctant to voice their emotional, practical and mental concerns, children feared causing further upset or anger to their parents [5, 13, 18, 30, 34, 35, 36, 42, 43]. It was suggested by one author that when open communication was lacking, adolescents became more aggressive with friends and peers [5], whereas others reported on experienced feelings of loneliness, anxiety and depression [18] and sought information from alternative sources, such as generic and non-specific information from the Internet [35, 45]

On reflection, some parents reported it as their 'moral obligation' [13] to openly discuss and prepare their children for the death of their parent. Parents suggested this open communication provided opportunities to create memories together as a family before the death [39], maintained and strengthened trusting parent-child relationships [8, 20, 37], to share emotions and insecurities [33], to exercise the family's religious beliefs [8] and provided the children the permission to make their own independent choices, such as being with the parent when they were actually dying [19, 35].

3.2.4 Parental conflict and informing the children

The literature suggested that parents often had competing opinions on how to best support and protect their children [38]. Specifically, in relation to what was best to tell them, the amount of information that should be shared and the timing of this [21, 36, 38, 39]. Some studies suggested conflict was often a result of the ill parent denying the reality of the situation [18, 38, 39]. Furthermore, it was suggested parents found it difficult to prepare their children when they themselves had a lack of exposure and experience of death and were unsure of what to expect or how to navigate this experience [38]. It was suggested that in those families were the ill parent was not accepting the reality of their illness, the healthy parent who wanted to prepare their children reported feelings of frustration and isolation [39, 45] as well as anger and guilt in knowing they would be 'left with the children' [38]. For these healthy parents, it was suggested they had put their frustrations aside, to respect the wishes of the ill parent, while they could still exercise them [38]. Consequently, as a result of these disagreements, children were less well prepared for the death of their parent, and they reported feelings of exclusion, low self-esteem and resentment following the death [36, 42].

Several broken and fractured families through divorce and separation who were attending the support groups were reported to find it challenging to support their former partner in the interest of their children [21, 36, 41]. A support group mediator was suggested to bring these families together; however the studies did not explore what their role was [26, 41].

3.3 Strategies to manage the changing situation

During the terminal phase of the parent's illness, while the family are faced with new demands and challenges, the literature highlighted strategies viewed as supportive to families to manage the changing situation. The literature demonstrates these strategies through the following sub-themes: (1) tensions surrounding spending time together; (2) protective nature of maintaining routine; (3) maximising supportive networks; and (4) children's developmental perspective of cancer and death.

3.3.1 Tensions surrounding spending time together

A recurring theme across many studies was the importance for parents and children to spend quality time together before the death occurred to create memories [28, 19, 21, 30, 31, 32, 33, 36, 37, 39, 44]. Despite this, it was not always possible, where it was suggested that given the health decline in one parent, with reduced mobility and energy, and the other parent with increased financial, practical and parenting responsibilities, there were few opportunities to collectively spend time as a family [34, 42]. The literature suggests that due to these increased demands and pressures, some families experienced more arguments, tension and instability [42]. Additionally, where memories were not created, as a result of not accepting that death was inevitable, parents and children regretted not valuing the time they had left together in the bereavement period [18, 39,42, 44]. Contrary to this, those families that managed to spend quality time together, reported on the importance of this for creating and providing tangible memories, which were captured through photos, videos, music and crafts [19, 21, 30, 33, 36, 39, 41, 46]. Parents and children valued spending time together as a family, before the death of the parent, as it was suggested to be helpful in adapting to the changes following the death [21, 28, 31, 44]. Specifically, children reported satisfaction in reminiscing on positive memories in the bereavement period [28, 31,32, 44]. Parents felt this was important, as they feared their younger children would forget their dying parent [21, 39].

While ill parents reported feelings of fear, sadness and guilt that they would miss out on the development of their children and the milestones they would achieve [41], parents and children expressed their desire to maintain a positive atmosphere within the home, with strong and loving relationships, incorporating increased physical and emotional contact [21, 28, 37, 39, 42]. This value was reported important by children as it provided them with increased positive memories and attachments to their parents, despite the emotional impact of the impending death [21, 28, 39, 46].

The literature documents the importance for contact between the ill parent and their children, when that parent was actually dying [31, 39. 44, 46]. Some children were not given the opportunity to have final contact with their dying parent, were they reported feelings of sadness and resentment in their grief [39, 46]. While some children chose not to [39], many reported relief in having the choice to say goodbye to their parent [28, 31, 39, 44, 46]. This final goodbye was described as important for creating a final memory for the children and made the event concrete [31, 39, 44].

3.3.2 Protective nature of maintaining routine

Parents and children had a strong desire for normality and routine, despite the death of the parent being inevitable [9, 18, 21, 30, 31, 34, 35, 39, 44]. In spite of this, mundane activities were often interrupted due to the demands of the parent's illness, the changes occurring within the family dynamic and financial pressures [34, 37, 42]. These interruptions were suggested to be distressing and frustrating for the children [42].

For children, routine was described as a 'protective zone' [31] where they had opportunities to receive empathetic peer-support in sharing their anxieties [30, 31, 34, 35, 39, 42, 44, 46] and to have a sense of relief from the intense and distressing situation at home [5, 31, 39]. Maintaining routine, such as going to school, provided parents and children with distraction, comfort, security and stability, as well as emotional and physical release [5, 18, 20, 30, 31, 34, 35, 39, 42, 43]. Routine granted children the opportunities to spend time with friends, peers and significant others [5, 18, 31, 34, 39,44]. This routine, such as school, was suggested to provide parents with reassurance that their children would have supportive networks and environments available before and after the death to off-load their worries, concerns and fears [20, 21, 34, 39]. These factors were suggested to be supportive in facilitating better adjustment in children's grief pre and post death [42, 44, 46].

3.3.3 Maximising supportive networks

The disruptive nature of cancer led to increased financial, practical and physical pressures for both parents [37, 42]. While not all parents had opportunities to do so [37], it was suggested supportive for parents to maximise their supportive networks so they could manage their own healthcare and parental responsibilities [5, 20, 34, 37, 41]. Extended family members and friends were suggested supportive by parents to help with practical and mundane tasks, such as providing meals and helping with household chores, as well as the practical care of the children, such as taking them to school or activities [5, 20, 34, 37, 41]. Additionally, parents found it particularly helpful when they were made aware of financial benefits they were entitled to, given changes that often occurred in the parents' employment status due to the cancer [37]. This included being aware of grants to help pay for household expenses or travelling costs to and from hospital/hospice [37].

For parents and adolescents, having informal connections with other parents/adolescents at support services, who are experiencing the same as them, was supportive in knowing they were not alone [5, 20, 37]. For parents specifically, these services were suggested helpful in sharing practical and emotional strategies to help support and prepare their children for the death of their parent [20, 37]. This included art therapies [20].

Some fathers reported discomfort in attending support services and seeking help from family, friends and colleagues [37]. These fathers felt it exposed their emotional vulnerability and challenged societal stereotypes of being a man and the provider of the family. Some of the fathers believed seeking help 'would be a sign of weakness' [37]. These fathers suggested it was their wife who helped them understand and accept the need for help financially, practically and socially [37].

3.3.4 Children's developmental perspective of cancer and death

In the majority of studies included, most of the children highlighted their need to understand cancer and death. Many studies suggested that children had reduced feelings of loneliness and a sense of belonging when they had an improved understanding of the family situation [8, 18, 29, 30, 31, 34, 35, 43]. The factors highlighted by these studies to facilitate children's understanding of the pending death of their parent included being provided with practical and realistic information regarding how their parent's disease would progress, detail on what death would look like and when it was likely to happen, life after death in relation to where the dying parent would go, as well as family life following the death [8, 13, 29, 30, 31, 34, 35, 43]. This information was centered on the level of their understanding [5, 21, 31, 39, 42, 46].

While children of all ages wanted to have an understanding of what their parent's death would look like [21, 29, 39], it was suggested that young children *(typically ages 4-11)* had a need to understand the effects of the cancer and the treatment. When young children had the provision of this knowledge, it was suggested to be helpful in managing their fears and anxieties [19]. Furthermore, young children expressed their need to experience empathy. For these children, it was suggested reading books incorporating characters experiencing similar pain, normalised these events for children and created a sense that they were not alone [39].

As the health of the ill parent was deteriorating, while they were aware of the situation, many adolescents reported difficulty in accepting the death of their parent, where they demonstrated heightened levels of fear, anxiety and resistance [5, 18, 28, 31, 42, 45, 46]. For these adolescents, it was necessary for their parents, teachers and peers to understand that they may have chose to become withdrawn, so they could process the reality of the situation alone and prefer not to visit or speak with either parent [9, 31, 39, 45, 46]. Some adolescents reported starting the process of accepting and grieving the death of the parent before the event occurred, as part of their own coping. As a result, these parents needed to understand coping

mechanisms for dealing with death and grief vary and that adolescents may not respond in the expected way [31].

Many adolescents reported feelings of isolation, loneliness, frustration, and anger when their peers and friends could not express empathy and compassion to their situation [5, 18, 31, 39, 41, 42, 46]. To the contrary, teachers, chaplains and cancer charity volunteers/coordinators were identified as valuable individuals by parents and children in advocating children's peers and friends understand their situation [5, 20, 30, 39, 41, 42]. In doing so, adolescents were suggested to be more willing to open-up and share their feelings with friends or peers and was helpful in coping with the demands of everyday life [20, 33, 41]. The literature suggested additional means as to how teachers can be supportive to adolescents. This included being sensitive in their teaching of specific topics, e.g. adolescents may find it upsetting to read pre-scripted texts about family members in a foreign language [9, 39] and appreciating children's anxieties and pre-grief concerns may affect their concentration, motivation and scholastic performance [5, 42].

Children expressed their need to understand death [19, 31, 39]. Existentially and practically, children expressed their need to know the process of dying and what would happen to their parent when they would die [19, 31, 39] and, if applicable to families, the concept of heaven according to their religious beliefs [19, 31]. Within the studies, death was only described to children using the concept of heaven. The literature suggests this was constructed as helpful by children, as they viewed it as a place where their parent would not be suffering and see them again [19, 31, 39].

5. Discussion

This review has highlighted published findings on the challenges and support needs of parents and children when a parent is at end of life. However, findings are reflective of middle-class two-parent families who attend support groups and services. Other literature has demonstrated that support groups and services

are disproportionately underused by certain groups including men, families from complex and fractured dyads, as well as minority and low socioeconomic status (SES) and educated backgrounds [47, 48]. To this end, literature has further illustrated that children from low SES and educated backgrounds are at greatest risk of internalising problems, including anxiety, depression and PTSD, when a parent is at end of life [49, 50]. The current studies have not accounted for the challenges and support needs of these populations. Furthermore, over half of the 42% of couples divorced within the first ten years of marriage in the U.K. are estimated to have at least one child under 16 which contributes to an overall estimate of one-in-four lone parent families of dependent children in the U.K [51]. Additionally, the majority of families fractured through divorce and separation are from low SES backgrounds [52]. The current studies have not accounted for the profound and complex challenges and support needs of these families, as they navigate the end of life experience. Also, relevant studies included only reported parental deaths from cancer and has not considered the impact of other morbidities, such as AIDS. Proportionately, future research should devise more robust recruitment procedures to incorporate the needs of other morbidities and hard-to-reach families, outside of groups and services and reflect this population and society as a whole.

The identified needs from these studies were largely influenced by both the developmental understanding of children and parents wanting to protect their children. The findings, their relevance to other literature, limitations and unanswered questions are now discussed from the twenty-seven papers under two main themes: (1) protective parenting and preparing children and (2) coping and social support.

5.1.1 Protective parenting and preparing children

While all parents have an innate response to maintain responsibility and protection in the caregiving of their dependent children, parents may exert their protection and not prepare them for the death of a parent. It is possible that parents' denial of the reality of the terminal illness affects their emotional readiness

to prepare their children. For children less prepared, they have shown increased levels of hostility, resentment, guilt and anxiety in their grief, compared to their counterparts, who are prepared for the death of a parent [35, 39]. Longitudinal research has demonstrated the benefits of preparing children in that they are less susceptive to psychiatric problems, including clinical depression, if they are prepared for the death of a parent [49, 53].

It was clear from the studies analysed within this review that spending quality time together, before the death, was an important factor for children in facilitating better adjustment in their grief [19, 21, 28, 30, 31, 32, 33, 34, 36, 37, 39, 41, 44, 46]. Other literature suggests it encourages children to share memories they have with that parent, which are suggested helpful to reminiscence on, during difficult days, when they are grieving [54, 55]. Furthermore, it was suggested that identifying and maximising networks inside and outside the family reassured parents that their children would have supportive networks pre and post bereavement [5, 20, 30, 31, 33, 34, 35, 37, 42, 43, 44, 46]. These findings have been echoed in studies of aging and dying parents of children with developmental disabilities, where these parents have reported it reassuring and comforting to know people would care and love their children, when they no longer would be able to [56, 57].

Having the choice to be with the parent when they were actually dying was suggested helpful in adjusting to life post-bereavement for children [31, 39, 44]. Supplementary literature further suggests that children have reported the experience less traumatic than anticipated and seeing a dead body was less distressing, than they imagined [58, 59]. The studies did not explore pre-bereavement challenges and support needs of these families. For example, how was the impending death explained to the children before the event happened. While many studies suggested parents used the concept ‘heaven’ to explain where the dead parent had gone [19, 30 31, 39], it only serves as a non-biological understanding of death [60] and can be confusing to be understood based on the developmental maturation of young children [61]. As a result, it is important that biological underpinnings are described, so the child fully understands death is a permanent

state and they cannot ‘visit’ this place where their parent is ‘happy’. However, the studies in the review did not acknowledge this or provide reference as to how families with non-religious beliefs explained death in the pre-bereavement period to their children.

All of the studies in the review suggested parents found it challenging to know what to share or how to prepare their children for the death of a parent. To this end, other literature highlights children’s understanding of cancer and death is underpinned by their cognitive developmental maturation [62, 63, 64, 65]. With this, parents were suggested to find it supportive when they were provided with the words and language from the service coordinator/facilitators on how to prepare their children accordingly. Despite this, the studies did not report what these were. Additionally, not all families have access to support services, groups or coordinators/facilitators and therefore it is not understood how parents explain these complexities to their children in this absence.

Furthermore, despite children’s desire for more information, it is difficult to provide factual information given cancer is associated with an ongoing and changing journey of uncertainty. For example, the desire for a timeline as to when the death would occur, cannot be factually answered, as it’s impossible to predict when a death would occur. This is further influenced by variables including if the parent responds to any palliative or alternative treatments. To this end, the studies did not highlight how these questions and concerns were managed within families. However, it is important that health professionals are providing realistic indications when and where possible of poor prognosis, declining health and when death may be imminent.

5.1.2 Coping and social support

The review identified many coping and social support mechanisms suggested to facilitate better adjustment for the family, pre and post the death of the parent. For example, children’s desire to have

normality and routine was needed to have release and distraction from the intense situation at home [5, 9, 18, 20, 21, 30, 31, 34, 35, 39, 42, 43, 44, 46]. In conjunction with studies when a parent is receiving active treatment, maintaining routine, as best as possible during the illness, has been identified as instrumental in providing children with a sense of belonging and purpose [15, 66] and controls for problems in later life, such as alcoholism [67, 68]. Additionally, in line with Family Systems Theory [69] attempts to minimise distortions to the family routine, during illness, has been identified as a coping strategy for children to manage their stress and anxiety, associated with parental illness [70, 71].

In addition to maintaining routine, such as going to school, the studies in the review demonstrated that teenagers needed to spend time with friends and peers for emotional release [5, 18, 31, 39, 44]. Further to this, other studies suggest the desire to spend more time with friends and peers may be a result of the social behavioral changes that occur in adolescence [72]. Research illustrates that during adolescence, teenagers' relationships with their peers and friends become more intimate [73] that they would rather spend more time with others their own age, to exercise their own dependence and autonomy [74]. Another study suggests teenagers find their friends equally as important as their parents [75]. The authors interpret these findings in that it is important that teenagers have 'permission' to adapt to the changes that occur with adolescence, during the stressful period and teenagers may prefer on having conversations with their friends and peers, than their parent(s) about the illness.

Fathers' rejection of accepting support and help as a threat to their masculinity or role of being a father has been echoed in other literature, where they have suggested men attributed to a hegemonic masculinity see it as a weakness to avail of help and support [76, 77]. However, this finding was only reported in the one study which included non-Caucasian participants [37] and has been identified in previous literature as a trait in non-Caucasian men [78]. Also, the study did not acknowledge this cultural difference [37]. Additionally, this finding cannot be considered as a one size fits all, given different interpretations of masculinity, gender and personality [79]. Furthermore, the suggestion that it was the wife who encouraged these

men to accept support and help at end of life may be a result of pre-existing roles of parenting within the family.

Moreover, not all families may have supportive networks such as the extended family members, neighbours or community organisations to help with mundane and practical tasks, or have access to support groups or service facilitators/coordinators.

Young children expressed a greater need for physical contact with their parents within a positive home environment, pre and post the death [31, 42, 46]. Attachment theory may provide a plausible explanation for this increased contact where young children need a secure adult caregiver for normal social and emotional development to occur [80]. Furthermore, studies have suggested than when one parent dies, children display increased reliance on the other, which is important for facilitating the grief process and producing new and existing parent-child bonds [81, 82]. Despite the importance of attachment, these harmonious scenarios are arguably not representative for the reality of these families, where creating a positive home environment, with increased time sitting together, is amiably a skewed version of reality. Parental cancer and end of life is associated with increased levels of distress and anger for the whole family [82, 83]. Future research should report the reality for these families, including the negative effects.

All studies suggest power in open communication and family cohesion, where children were suggested to have reduced feelings of loneliness and anxiety and felt valued, when they were prepared for the death of their parent. Other studies advocate this communication within families as a coping strategy for children when a parent is ill [84]. It has been suggested to reduce children's anxiety by having opportunities to freely talk with their parents about their cancer [85], reduce mistrust between parents and children [86] and reduce PTSD symptoms when they can openly talk with the healthy parent, about their ill parent, after the death [87]. Open communication during illness has also been suggested to manage conflict and create

a more cohesive parent-child environment [87, 88, 89] as well as stronger and dynamic relations among couples [90, 91].

5.2 Limitations and directions for future research

All studies were conducted between Australia, U.K, Scandinavia and the USA. This raises concerns as to how the identified challenges and support needs extend to non-Western populations or ethnic minorities living in Western societies. It is important for future research to consider more heterogeneous samples of families; for example parenting and child rearing practices in non-Western cultures may impact on the challenges and support needs of parents and children, when a parent is at end of life.

Although all included papers were assessed by the three authors [JH, EMcC, CS], the initial screening was only conducted by the first author [JH]. While careful consideration was given to this process with papers screened by title and abstract on more than one occasion, it is possible relevant articles may have been missed.

Some of the studies in the review reported positive factors suggested to facilitate better adjustment for families, when a parent is at end of life. Despite this, in the absence of longitudinal follow-up with these families, it is difficult to assess the impact these factors had, in the long-term adjustment for these families. In addition to this, the studies did not provide specific details on many factors suggested to be supportive, to which future research should explore. For example, (1) the role of teachers, chaplains and charity volunteers (2) what leaflets, websites, forums and role-plays are helpful; and (3) how do health professionals facilitate conversations in broken and fractured families as well as between parents, who can not mutually agree on what to share with their children, when a parent is at end of life. Furthermore, it is not typically

the norm in clinical practice for children to have access and conversations with health professionals. As a result, it is unclear where children's questions are directed in this absence.

Within the literature, there is an inconsistent use of terminologies. While the current review investigated 'end of life', some researchers may refer to this as 'advanced' or 'terminal'. Although the search strategy deployed was sensitive to this, it is possible that research papers were missed due to different interpretations of these terminologies.

All of the studies in this review addressed the support needs of families impacted by parental cancer at end of life, but future research should also represent the needs of parents with life-limiting, non-malignant disease, who have dependent children. While research studies have investigated parenting with other chronic conditions (such as HIV/AIDS) [92, 93], and while patterns and similarities may occur in these papers, they were not included in the current review as they did not match the study inclusion/exclusion criteria. Specifically, they did not make it clear if the parent was at end of life. Papers were only included if they specifically made it clear that parent had the awareness they were going to die, very likely within a one-year period. Finally, for parents to comprehend and process their illness and situation, there is a need for health professionals to provide parents with factual and accurate information regarding their prognosis.

5.3 Conclusions

This review has identified that parents need to openly communicate and prepare their children to facilitate a better adjustment when their parent is at end of life. The findings demonstrate parents lack of understanding in relation to the parent's prognosis and impending death, denial, feeling ill-equipped, as

well as tensions between parents were identified barriers in sharing the news with their children. Additionally, this review highlights that parents have a desire and need for a clearer indication from healthcare professionals when the parent's prognosis is poor and death is imminent, so they can prepare their children for the impending death of their parent. The studies highlighted coping mechanisms suggested to be supportive for parents and children when a parent is at end of life. This included supportive friends, peers, neighbours, relatives and community groups such as the school. Despite this, studies often did not report the negative effects or reality for many families. For example, findings are not generalisable to the entire population, as they are reflective of middle-class two parent families living in Western societies who attend support groups and services. To best support families when a parent of dependent children is at end of life, future studies should consider more heterogeneous samples of families, such as complex family dyads and individuals from lower educated and SES backgrounds.

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